

Supporting individuals with disabling multiple sclerosis

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People with disabling multiple sclerosis (MS) can lead rewarding and fulfilling lives. To this end, they will do best if they adjust early to the diagnosis and its implications, if disabling symptoms are kept to a minimum and if they get all possible support (including the use of assistive technology) from both professional and voluntary sectors. Support may be needed by those whose disability is static, those who have relapsed and those whose course is progressive. This review explores how this can sometimes be achieved.

The diagnosis of MS is a devastating event for individuals, their families and friends^{1,2}. Its unpredictable course creates difficulties for psychological adjustment and for planning appropriate support³. The development of new disease-modifying drugs seems to have reduced relapse rates for some but may not alter long-term disability. Advice regarding the use of disease-modifying agents is beyond the scope of this review but has recently been distributed in the UK⁴. Only a small proportion of people with MS proceed to severe disability, many remaining independent 20 years or longer after diagnosis. However, subsequent progression to more severe disabilities is the experience of many. Rehabilitation is effective in reducing 'disability and handicap'⁵ and 'disability'⁶ and is an essential part of management¹.

Living with MS typically is complicated by³:

- Initial difficulty in making the diagnosis
- Uncertainty of relapse, remission and progression
- Absence of cure
- Diversity of symptoms and disabilities
- Many family doctors having little experience of the disease
- Neurologists having inadequate time with individuals initially and for follow-up
- Complex co-morbidity—e.g. depression and pain.

As traditional medicine aims to provide 'disease intervention', many doctors feel ill equipped to help those with an incurable disease³. Much, however, can be done to

help; and, because of the diversity of cognitive, physical, psychological and social problems experienced, rehabilitation requires a coordinated multiagency approach by health and social services^{3,7} including:

- Acute general hospital (diagnostic and support teams, e.g. urology)
- Inpatient rehabilitation services linked to
- Community rehabilitation teams
- Daycare or domiciliary respite (e.g. crossroad care attendants)
- Residential respite care.

Consequently, matching the individual's needs to relevant services is crucial to the success of rehabilitation with different services needed, for example, to restore function after a relapse, to facilitate living with a chronic disability, to respond quickly when there is rapid deterioration and to provide assistive technology (e.g. wheelchairs). Each function should be part of a coherent service⁷.

DIAGNOSIS

Early adjustment greatly facilitates later management. Hospital specialists and general practitioners (GPs) should liaise from the earliest stages to support the individual and family. Ideally, adjustment is aided by psychological support but this is seldom available. The first interview may need to be relatively free of detail, as the patient is unlikely to remember much after the emotional assault of being given the diagnosis. Information from the Multiple Sclerosis Society (MSS)⁸ should be available and a second consultation should be arranged, with the patient and partner being encouraged to bring a list of written questions⁹. This is likely to be a period of doubt and despair, and the second interview can restore confidence. Some are helped by contacting the MSS whilst others find this distressing.

Honesty with the patient is usually the best policy. If diagnostic uncertainties exist, a straightforward explanation can be promised when the situation has clarified. Often patients experience a grieving process including emotional shock, anger, depression and denial^{3,10}.

A balance needs to be found between over-accepting MS and denying it³—see Figure 1.

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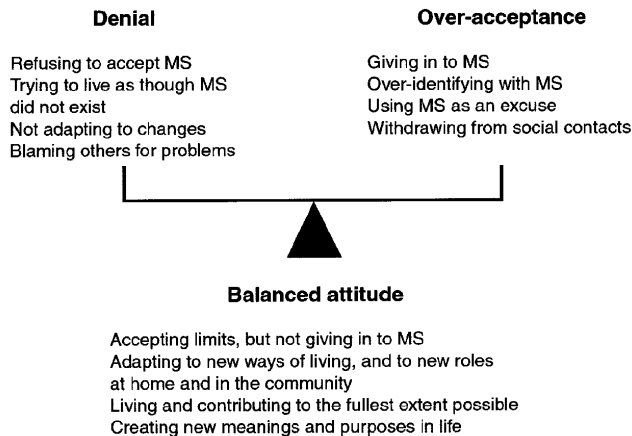


Figure 1 **Coming to terms with MS** (Reproduced with permission from *Multiple Sclerosis: a Personal Exploration* by A Burnfield, Souvenir Press, London, 1985)

MANAGEMENT OF DISABLING SYMPTOMS

Pain

Estimates vary about the prevalence of pain experienced by individuals with MS, which includes trigeminal neuralgia, Lhermitte's phenomenon, burning pain and pain related to optic neuritis and spasms. Trigeminal neuralgia may be mimicked by dental abscesses or cavities. Generally neurogenic pains respond well to anticonvulsants or tricyclic antidepressants. Neurodestructive procedures on the trigeminal ganglion, e.g. radiofrequency or balloon compression, may give pain relief for as much as five years.

Another common trouble is musculoskeletal pain which, though not directly attributable to the MS, results from prolonged immobility, poor posture and gait abnormalities. Thus the cause of pain needs evaluation³.

Spasticity can lead to:

- Pain and pressure sore development
- Difficulty in clearing lung secretions
- Problematic transfers
- Disturbed sleep
- Poor perineal hygiene
- Bad posture
- Contractures, exaggerating the loss of mobility and grip.

By limiting the capacity to exercise, spasticity can lead to cardiovascular deconditioning and exacerbate muscular weakness. Therapeutic goals for spasticity management should be identified with the multidisciplinary team, and treatment should be systematic, with good documentation¹¹. Individuals with MS need to understand the importance of time for exercising and stretching so that

the new movement patterns can be made a part of everyday living. Carers can learn to help by becoming involved in management.

The team's approach to management must be acceptable to the individual, and if possible also to the family⁸. Treatment can be divided broadly into physical, medical and surgical (Box 1). Neurophysiotherapists are invaluable in the management of severe spasticity, assessing its pattern, severity and likelihood of improvement with therapy. Identification of contractures is a prerequisite to defining possible goals; for instance standing with minimal support might be assisted by medication, therapy to stretch and strengthen appropriate muscle groups, injection of botulinum toxin into calf muscles¹¹ or release of tendo achilles. After chemical denervation, intensive stretching of shortened muscles is critical to improvement. Continuing therapy is seldom available on the National Health Service (NHS) and carers may need to be taught techniques of stretching.

Incontinence

Urinary troubles are common and sometimes lead to social isolation through fear of incontinence. The aims of management are to preserve renal function and alleviate symptoms, the commonest being incontinence¹². Measures available are summarized in Box 2. Residual volumes

Box 1 Management of spasticity

General—removal of stimuli

Constipation
Urinary infections
Ingrown toenails
Pressure sores
Fractures

Physical

Seating posture
Tilt tabling
Stretching and strengthening
Gait training
Serial casting and orthoses

Medication

Diazepam
Baclofen
Dantrolene
Tizanidine

Invasive medication

Intrathecal baclofen
Intrathecal phenol
Nerve blocks
Botulinum toxin

Surgical

Tenotomies
Rhizotomy
Spinal cord and cerebellar stimulation

(measured by catheter or ultrasound) greater than 100 mL require drainage¹³. If the individual is unable to self-catheterize (for example, because of visual impairment, adductor spasticity, tremor or weakness) carers may be taught intermittent catheterization.

Many individuals experience constipation, and this can be difficult to treat. Overflow faecal incontinence greatly complicates living in the community. Management includes high fibre diet, sufficient fluid intake, avoidance of constipating medication, use of the gastrocolic reflex, unhurried defaecation and digital stimulation. For many, planned bowel evacuation (e.g. on alternate mornings after breakfast) relieves the fear of possibly needing to defaecate at inconvenient times or in inappropriate places. Faecal incontinence not secondary to constipation may respond to anticholinergics.

Cognitive loss

Impaired cognition may be profoundly disabling³ and is a major cause of inability to work¹. Specific deficits include poor memory, slow information processing and impaired learning. Detailed neuropsychological assessment, if available, can lead to a more tailored rehabilitation programme¹⁴. Less commonly, personality and behaviour may change. Partners and family must recognize that cognitive deficits are present and that these reflect the disease process.

Fatigue

Fatigue is common, reflecting muscle weakness, exhaustion (irrespective of activity) and sleep interruption (e.g. from nocturia or spasms).

Employers, relatives and professionals may misunderstand fatigue. It can dominate individuals' lives, commonly being exacerbated by heat and exertion. It is often felt as 'flu-like', with disturbances of vision, speech, mobility, coordination and sensation after minimal activity. Concentration and memory may be affected. Depression can exacerbate fatigue, as can the increased energy requirements for ambulation or transfers. It is important to explain to the individual and family the possible reasons for fatigue. Helpful strategies are to pace activities throughout the day, to take rest periods and to take gentle exercise such as swimming in a cool pool. Amantadine and modafinil¹⁵ are occasionally prescribed but their place in management is not yet established.

Immobility

Walking is usually affected if the disease is progressive, through a combination of weakness, spasticity, fatigue, disuse, pain, cerebellar ataxia and sensory loss (particularly

Box 2 Management of incontinence

General

- Good fluid intake (3L per day if tolerated)
- Perineal hygiene
- Adjustment of urine pH
- Pelvic floor exercises/bladder retraining
- Pads, Conveens

Medication

- Anticholinergics
- Desmopressin
- Antibiotics for urinary infections (occasionally prophylactic)

Invasive medication

- Intravesical capsaicin/resiniferatoxin

Catheters

- Urethral—intermittent or indwelling
- Suprapubic

Surgical

- e.g. ileal loop diversion

Box 3 What is learned from the home visit? (modified from Ref. 17)

Medical/physical

- Screening for illness—e.g. urinary infections
- Pain management
- Swallowing/communication

Psychological

- Emotional agendas
- Fears/worries
- Relationship issues—illness/pain behaviour—effects on partner
- Partner's health and emotional wellbeing

Environmental

- Transfers—e.g. on/off bed, chair or toilet
- Stairs—banister, grab rails, stair elevator/lift
- Toilet—bucket in kitchen, upstairs toilet?
- Wheelchair use and access
- Potential for environmental controls

Independence

- Bath aids, commode by bed
- Mobility aids—e.g. elbow crutch, trolley

Transport

- Transfer into car, safety issues

proprioception)^{14,16}. Inability to take weight through the legs can prevent major transfers (Box 3).

The prevention of lower-limb contractures and maintenance of muscle strength with regular physiotherapy may facilitate mobility but needs careful planning to avoid fatigue. For those who are severely disabled, domiciliary physiotherapy avoids long trips to hospital; moreover, therapy in the home environment (e.g. on carpets) has other advantages.

Mobility may be maintained with walking aids, orthoses, 'environmental management' (e.g. strategically placed grab rails) and wheelchairs. A wheelchair should be considered

Box 4 Impact on carers

Partner
Poor health (back pain, depression)
Social isolation—e.g. giving up work to care for partner
Sexual difficulties (effects of MS on libido, orgasmic potential, sense of being unattractive, potency in men, adductors in women)
Financial hardship
Children
Additional household chores
Reduced social opportunities
Increased parental nagging
Lost parental support and advice
Anxiety, fear, bitterness
Fear they will get MS
Parents
Need to provide support for grown-up children and grandchildren

either when the individual becomes unable to walk or when the time or energy consumed by walking reduces functional ability.

Outdoor powered mobility can increase the freedom of the individual and the carer¹⁸. Driving gives freedom and independence, often enabling a person to continue working. Those wishing to drive can be assessed at driving assessment units (see Mobility and Advice centre—Appendix 1). If intellect, vision and reaction/decision times are not impaired many can drive suitably modified cars.

Pressure sores

Sensory loss, immobility and incontinence are each major risk factors for developing pressure sores commonly seen in MS¹⁹ (e.g. sacral sores from lying supine and ischial sores from prolonged sitting). Strategies for their prevention include encouraging postural changes, spasticity management, incontinence management, good sitting position, pressure-relieving beds, and sheepskin-lined trolleys, slings or bootees and smoking reduction. These need consideration before transportation or planned admission to hospital or respite care.

Communication and dysphagia

Speech problems are usually due to weakness, poorly controlled breathing, or dysarthria, singly or in combination. Communication can be helped in some cases with speech and language therapy. Sometimes simple measures (e.g. supporting the neck and spine together with coordinating breathing with speech and relaxation techniques) may help—see communication aids below.

Dysphagia needs assessment by speech and language therapists, usually with access to specialist investigations.

Tremor and extrapyramidal symptoms

Tremor is usually an action tremor reflecting cerebellar dysfunction. Conservative measures such as use of weighted armbands and large-handled implements may help. Resistant tremor may warrant botulinum toxin injection²⁰ or stereotactic surgery²¹.

Metabolic bone disease

Osteoporosis is not infrequent in wheelchair-dependent individuals²². Other contributing factors include steroid therapy, being housebound, vegetarianism (sometimes with vitamin D deficiency), smoking and alcohol abuse. Management, which is changing rapidly, may include regular exercise (when possible), calcium and vitamin D, stopping smoking and treatment with bisphosphonates.

Osteoporotic femoral fractures, which have been reported in paraplegic people with MS²³, may be asymptomatic and detected incidentally.

PSYCHOSOCIAL PROBLEMS

Depression is said to be common in MS, although this was not borne out by a recent study in a severely disabled group². Where present it may hamper rehabilitation through reduced motivation. Antidepressants may work well. Other mood disturbances include emotional lability and uninhibited crying or laughing, euphoria and anxiety. Irritability and inability to empathize with others can contribute to relationship breakdowns. These, together with the fear of public embarrassment through urinary incontinence or spasticity, may result in social isolation, often also experienced by the carer.

Sexual difficulties can reflect exhaustion, disturbed mood and practical elements (Box 4). Impotence may be helped with penile prostheses, intracavernous injections and sildenafil. The Association to Aid the Sexual and Personal Relationships of People with a Disability (formerly SPOD) can often be helpful (Appendix 1).

Potentially three generations are affected by a diagnosis of MS. Partners and other family members may need both physical and emotional support²⁴; effects on children are often ignored (Box 4)^{14,25,26}.

Psychosocial management

A comprehensive assessment should include personal and domestic skills, mobility, accommodation, legal matters, employment, finance, social and leisure activities and potential problems with relationships.

Work can provide a sense of identity, status, achievement and personal satisfaction, as well as money¹⁰. Reasons for unemployment include²⁷ fear of discrimination, lack of confidence, low self-esteem and the poverty trap (allowances exceeding earning potential).

Table 1 Potential benefits available to those with multiple sclerosis

Circumstance	Benefit
Incapable of work	
Employed	Statutory sick pay
After 28 wk SSP, or not employed	Incapacity benefit
Not enough NI contributions for incapacity benefit, and you are 80% disabled or incapable of work since before age 20	Severe disablement allowance
Caring	
You care for a disabled person for at least 35 h a week	Invalid care allowance
Problems with walking	
Aged under 65 when you claim	Disability living allowance mobility component
Hire or buy a car using the mobility component of DLA	Motability
If you get higher rate mobility component	Road tax exemption
Parking concessions	Orange badge scheme
Need help with personal care	
Aged under 65 when you claim	DLA care component
Aged 65 or over when you claim	Attendance allowance
Severely disabled and need help with personal care or household assistance	Independent living funds
Working at least 16 h per week	
You have a disability and get a qualifying incapacity or disability benefit	Disability working allowance

SSP=statutory sick pay; NI=National Insurance; DLA=disability living allowance

For those in employment factors to consider²⁸ are openness with the employer, job modification (tasks or environment), reduced or flexible hours, and travel or driving assistance. The disability employment adviser at the local job centre can help those seeking employment²⁸. Many need advice about benefits, and this can be obtained from charities or the Citizens' Advice Bureau (Table 1).

COMMUNITY SUPPORT FOR THOSE SEVERELY DISABLED BY MS

Most individuals can be supported in the community with dignity³. This requires the close collaboration of employment, housing, health and social services^{28–30} and the recognition of the social dimension by health professionals. The cementing of links between hospital and community (health and social) services is facilitated by a case conference where a GP's knowledge of affected individuals and their families is often crucial. A home visit is usual to understand the individual's perspective and practical problems (*see* Box 3). Professionally guided self-care, focused on individual interests and concerns, improves health status³¹. The teamwork requires a carefully formulated strategy for community support²⁹. Occasionally individuals do not wish to remain at home when residential care can be arranged, for example through a Cheshire Home.

Carer respite may be provided by holiday relief (social services, or charities such as Winged Fellowship Trust, Appendix 1), by domiciliary respites (professional or voluntary services such as Crossroad Care-attendant schemes, Appendix 1), and by day centres.

Box 5 Reasons for breakdown of community support

Intrinsic	Extrinsic
Increasing paralysis or sensory loss	Lack of recuperation time (caring for 24 h/day)
Intellectual or speech defects	Denial of problems
Personality change (particularly loss of humour)	Conflict of care—e.g. with work
Fatigue	Isolation
Loss of confidence—e.g. after a fall, incontinence	Poverty
Boredom—loss of meaning to life	Ill-health (backache, hypertension)
Infections	Fatigue (heavy load, getting heavier)
Drug or alcohol abuse	Role change
Pressure sores	Sexual change
	Sexual frustration
	Loss of future—living with no hope of a cure

Risk factors for the breakdown of the support network are both intrinsic (within the client) and extrinsic (within the family, home, or community)³², Box 5.

ROLE OF THE MS SOCIETY AND OTHER GROUPS

The MSS has a national centre in North London and about 370 branches throughout the UK. Box 6 summarizes its many functions. The branches are mostly run by volunteers who either have MS themselves or a family member affected. These self-help groups allow members to meet others with the disease, and provide enormous emotional support. They also allow those with MS to feel that they are helping others.

Excellent publications and library facilities for patients, carers and professional staff are also available from the Multiple Sclerosis Trust. Other charities providing assistance for those with MS are listed in the leaflet *MS: Who Can Help?* available from the MS help line. Details of other local voluntary bodies are found in local libraries or the community section of telephone directories.

ASSISTIVE TECHNOLOGY

Communication aids

Communication aids are available to enhance, or replace, speech. They require linguistic ability and cognition. Three different types exist:

- Direct select—choice indicated directly by any part of the body (e.g. Lightwriter)
- Scanning—options scanned and user indicates item of choice
- Encoding—user choosing from patterns or symbols indicating a phrase.

Other types of communication aids include a radio pendant to summon assistance, an adapted telephone and upstairs/downstairs intercoms.

Environmental controls

Environmental control units facilitate environmental manipulation with minimal physical effort³³. Most household services controlled through electricity can be worked through such a unit, for example:

- Door opening
- Electrically operated beds or through-floor lifts
- Emergency alarm
- Intercoms—e.g. when sleeping downstairs with carer upstairs
- Lights
- Radios/televisions/videos
- Telephones.

Box 6 Roles of the Multiple Sclerosis Society

Branch network provides:

- Self-help groups
- Funds for those with financial problems
- Help to obtain grants from other organizations—e.g. towards a respite holiday
- Second-hand equipment for sale

Information in the form of:

- A bimonthly magazine *MS Matters*
- Information booklets
- Videos and tapes
- Website, [www.mssociety.org.uk]
- Free phone line (08088008000)
- Telephone counselling service: London 020 842 22144; Scotland/Northern England 0131 226 6073

Research funding

Voluntary workers may:

- Attend case conferences
- Help the professionals see the problems from the sufferers' point of view
- Act as an advocate

Respite care centres and holiday homes

Service support—e.g. MS specialist nurses

Environmental control units are available freely through Department of Health designated medical assessors (usually rehabilitation medicine consultants).

Wheelchairs

Powered wheelchairs include indoor electric chairs and indoor/outdoor chairs. They may be available on the NHS for those unable to walk or self-propel. There is no NHS provision of purely outdoor powered chairs. Hand, foot, head, chin or mouth may operate control switches. Such chairs enhance independence and reduce carer strain^{17,33}.

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APPENDIX 1: USEFUL ADDRESSES

Driver and Vehicle Licensing Agency (DVLA) Swansea SA6 7JL; Tel: 01792 772151 [www.dvla.gov.uk]

Mobility Advice and Vehicle Information Service, Macadam Avenue, Old Wokingham Road, Crowthorne RG45 6XD; Tel: 01344661000 [mavis@detr.gov.uk]

Multiple Sclerosis Society, MS National Centre, 372 Edgware Road, London NW2 6ND; Tel: 020 8438 0700 [www.mssociety.org.uk]

Multiple Sclerosis Trust, Spirella Building, Bridge Road, Letchworth SG6 4ET; Tel: 01462 476700 [www.mstrust.org.uk]

The Association to Aid the Sexual and Personal Relationships of People with a Disability, 286 Camden Road, London N7 0BJ; Tel: 0207 6078851 [www.spod-uk.org]

The Crossroads Care Attendant Scheme, 10 Regent Place, Rugby CV21 2PN; Tel: 01788 573653 [www.crossroads.org.uk]

Winged Fellowship Holiday Trust, Angel House, 20–32 Pentonville Road, London N1 9XD; Tel: 020 7833 2594 [www.wft.org.uk]